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ABSTRACT

The first of three reports from a study of developmentally disabled persons living with their families, this document presents findings on the first group (group A) studied: Washington's Division of Developmental Disabilities (DDD) clients 16 and older who currently live with their families. The closest relatives or guardians were interviewed and DDD specialists given surveys. Within Group A, three age groups were identified: 16-21, 22-19, and 30 and above. Findings are presented for three major topic areas: client and family characteristics (demographic data, physical, mental, and dental health); client/family activities (client decision making, friendship and social activities, and risk and safety); and current and future client status (family's goals and arrangements, preparation for adult living). A description of the methodology used and a set of data tables are appended. (CL)

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Report:

DEVELOPMENTALLY DISABLED PERSONS IN FAMILY SETTINGS:

REPORT NO. 1

DIVISION OF ADMINISTRATION AND PERSONNEL

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DEVELOPMENTALLY DISABLED PERSONS IN FAMILY SETTINGS: REPORT NO. 1

Division of Developmental Disabilities Clients Currently Living with Their Families

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March 1985

Program Research and Evaluation Section
Office of Research and Data Analysis
Department of Social and Health Services
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EXECUTIVE SUMMARY

In 1983 the Division of Developmental Disabilities (DDD) within the Washington State Department of Social and Health Services initiated a study of developmentally disabled persons who were living with their families. Study goals were to describe this population and to examine the status of families who care for developmentally disabled relatives at home. This report, the first in a series of three, presents major findings regarding the first group studied: DDD clients, ages 16 and above, currently living with their families. Three age groups (16-21, 22-29, and 30+) were identified, based upon anticipated differences in their needs and circumstances. A statewide random sample was selected for each age group, and data were collected from each client's closest relative or guardian and Developmental Disabilities Specialist. Key findings are summarized below.

What are the characteristics of developmentally disabled persons who live with their families?

- Of those who were mentally retarded, two-thirds were in the borderline to moderate range. Degree of mental retardation did not differ significantly among age groups.

- Most clients were independent in all areas of personal care except for grooming; they needed more help with independent living tasks, especially money management and shopping.

- Most were considered capable of managing common risk situations.

What are the daily activities of clients?

- Half spent at least 25 hours per week in work, school or training programs.

- Over 80% had at least one friend, yet half had not had friends over to their houses in the previous month.

- At least 75% had been to restaurants, had shopped and had visited friends or neighbors during the past month.

What family support services do families receive and what supports are needed?

- Twenty-seven percent had received one or more family support services from DDD within the past year, usually respite care.

- Nearly half reported needing family support services. Services most needed were therapy, counseling and respite care.

- Thirty-eight percent of the families did not receive any support services from DDD and reported no need for them.

- Families of the youngest group were most likely to receive DDD family support services (43%) and to report a need for them (57%).

What is the current status of DDD clients according to DD Specialists?

- DD Specialists indicated that most clients got along adequately with family members (80%) and were given opportunities to contribute to the family unit (65%); about half were reportedly treated as adults and encouraged to become more independent.

- The most common concerns expressed were that clients had no job or training program (25%), were isolated from their peers (25%), needed training in social and community living skills (25%) or lived in an overprotective home environment (22%).

What are the family's goals and what arrangements have been made for the client's future?

- Two-thirds considered a sheltered work environment to be the most suitable long-range vocational goal for the client.

- Twenty-six percent expected the client to move away from home within two years; families of the youngest clients were most likely to expect such a move (50%).

- Parents most often preferred that the client continue living at home (51%) or move to supervised group living (23%) as a permanent residence.

- Two-thirds had made financial and/or sponsorship arrangements for the client's future.

What is being done to prepare young clients (16-21) for adult living?

- About three-fourths were attending school, and most students were receiving vocational training.

- Most non-students (72%) had completed school or reached 21 years of age, and half were employed or participating in work-related training.

What arrangements are being made for older clients (30+) when the family can no longer care for them?

- Two-thirds of the parents preferred to have the client remain at home as long as possible. Ultimately, most families expected the client to live in a friend or relative's home (36%), in a supervised group setting (28%), or independently (12%).

- Families of the older clients were the least likely to receive DDD family support services (19%). 45% reported a need for such services, most often therapy and family counseling.

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CHAPTER I. STUDY OVERVIEW

Background

As of November 1983, over 40 percent of the nearly 12,000 developmentally disabled persons in Washington State who were clients of the Division of Developmental Disabilities (DDD) lived with relatives. This group included more persons than those in all DDD-sponsored institutional and community residential settings combined. Public policy in Washington State has generally encouraged families to support relatives, adults as well as children, who cannot live independently. In order to plan effective support services to families with developmentally disabled members, information was needed on the status of families who cared for developmentally disabled relatives. The present study was initiated in 1983 to fill this void.

The study addressed developmentally disabled persons in Washington State, ages 16 and above, who live with their families or were living with their families at age 18. Study groups included current clients of the Division of Developmental Disabilities, as well as persons who appeared eligible but were not DDD clients.

Data about developmentally disabled adults, whether or not they receive DDD services, provides insights about demand and utilization of resources. These findings have a bearing on DDD planning, especially in light of the Habilitation Rights Act (RCW 71.30), passed in 1983. This Act mandates the Division to provide, within available funding, adequate habilitation to every eligible developmentally disabled person.

Study Goals

The goals of this study were to compile descriptive information about this population and to provide data the Division might use to assess the adequacy and appropriateness of family living for these persons. Data were collected to answer the following key research questions:

1. What are the characteristics of developmentally disabled persons who live with their families? What are the characteristics of their families?

2. What factors contribute to the family's decision to keep a developmentally disabled member in the home or seek another residential alternative?

3. For those who moved from the family home after age 18, where do they live and what factors were associated with their leaving?

4. How do eligible developmentally disabled persons who are not clients resemble DDD clients, and how do they differ?

Approach

In order to address these questions in a thorough yet timely manner, three distinct groups were studied in succession. Each group is briefly described below (Table 1.1).

TABLE 1.1

DESCRIPTION OF STUDY GROUPS

	Population	Primary Focus
Group A	DDD clients now living with their families.	Describe the characteristics, activities, and status of the overall group; determine any age-group differences.
Group B	DDD clients living with their families at age 18, now living elsewhere.	Describe the characteristics and status of these clients prior to their leaving home; compare with Group A to identify factors related to out-of-home placements.
Group C	Non-DDD clients who appear DDD-eligible regardless of where they live.	Describe this "latent population" for DDD services and contrast with Groups A and B.

The closest relatives or guardians of selected developmentally disabled persons were contacted and asked to participate in the study. For DDD clients studied, information was also solicited from Field Services records and from each client's Developmental Disabilities Specialist, i.e., case manager. Two data collection methods were used: (1) structured telephone interviews with relatives or guardians, and (2) a mail survey of DD Specialists. Data collection instruments for each study group covered much of the same general information, as well as unique items applicable to special subgroups.

The remainder of this report pertains to Group A only. Methods and findings for Group B and Group C are presented in separate reports.

Group A Overview

The first phase of this study examined DDD clients in Washington State who were currently living with their families (Group A). "Living with families" was operationally defined as sharing a private residence with a relative or legal guardian, excluding living with one's spouse or children. (Throughout this report the terms "parents" and "family" are used generically, to include legal guardians or close relatives other than parents.) Data collection efforts were designed to examine the demographic characteristics and histories of clients living with their families, their functional abilities, needs for support, current health, and their daily living experiences. Research also focused upon the family living situation--family interactions and adjustments to the client's continued presence in the family home, resources and services used, and goals and expectations for the developmentally disabled family member.

Within Group A, three age groups were identified based upon assumed differences in the needs or circumstances of these clients and their families. These age groups were: youths (ages 16 through 21), young adults (ages 22 through 29), and adults (ages 30 and above).

The 16-21 age group was considered of particular interest because these clients were making -- or were about to make -- a transition to adult living. Also, at this time developmentally disabled youths and their families often consider the youth's possible move from the family home. Therefore, two research questions were addressed for this age group specifically: What is being done to prepare them for adult roles and independent living? How likely are they to remain in the family home?

Young adults, ages 22-29, were identified as a priority because these were deemed critical years in determining their future living arrangements, work, social life, and sources of support. Data about this age group would be contrasted with results for the older and younger groups; it would also serve as the basis for making comparisons with DDD clients who no longer live at home (Group B) and developmentally disabled adults who are not enrolled with DDD (Group C).

Adults, ages 30 and above, were of special interest due to concerns about continued family living for developmentally disabled adults as their families grow older. Given circumstances such as parents approaching retirement age and other children leaving home, it was anticipated that these families might have more immediate need for support services or residential alternatives for their developmentally disabled relative. In light of these issues, research about this age group addressed the additional question: What plans have been made for the long-term support needs of these clients?

For each age group a statewide random sample of 250 clients was drawn from a file of all DDD Field Services clients (Table 1.2). Comparison of sample and population distributions by sex, type and extent of developmental disability, and urban or non-urban status indicated that samples were clearly representative. Information about each sample was collected from three sources: (1) the population file of all DDD Field Services clients, (2) the client's nearest relative or guardian ("parent"), and (3) the DD Specialist assigned to each client. Most descriptive data were solicited from parents because they have more opportunity to observe the client regularly. Therefore, unless otherwise stated, findings discussed in this document are based upon parent reports.

TABLE 1.2

POPULATION SIZE AND NUMBER
OF COMPLETED INTERVIEWS
BY AGE GROUP

	16-21	22-29	30+	TOTAL
Number of completed interviews	195	192	190	577
Total number of DDD clients living with their families	714	812	547	2073

Note. Sample sizes were sufficient to generalize study findings to the population with an error margin of approximately seven percent at the 95 percent level of confidence.

Tests of statistical differences between age groups were performed on all data reported in the tables. Findings were considered statistically significant at the 95 percent confidence level ($p < .05$). In other words, sample differences would have occurred by chance only five percent of the time or less if there were no differences in the population. (Additional information about study methods appears in Appendix A.)

Results of parent interviews, as well as supplementary data from DDD Field Services, are presented in subsequent chapters. Chapter II summarizes characteristics of clients and their families, Chapter III describes their daily activities, and Chapter IV discusses their current status and future plans.

CHAPTER II. CLIENT AND FAMILY CHARACTERISTICS

Information from parents and DDD Field Services staff has been used to develop a profile of the developmentally disabled clients studied. The chapter begins with demographic data about the clients and their families, e.g., distribution of clients by sex and race, average family size and income, and type and extent of developmental disabilities. The next section presents findings about clients' physical, mental and dental health. Client functioning in the areas of personal care, independent living, communication, risk management, and social behavior are described in the final section of this chapter.

Demographic Data

Demographic characteristics of clients are presented in Table 2.1. The composition of each age group was similar in terms of sex, locale, and

TABLE 2.1

CLIENT CHARACTERISTICS
BY AGE GROUP

	16-21		22-29		30+		TOTAL	
	%	n	%	n	%	n	%	n
Sex:								
Male	61	(118)	57	(108)	51	(96)	56	(322)
Female	39	(76)	43	(82)	49	(93)	44	(251)
Locale:								
Urban a/	80	(156)	80	(153)	78	(149)	79	(458)
Non-urban	20	(39)	20	(39)	22	(41)	21	(119)
Race:								
Asian	0	(1)	0	(0)	2	(4)	1	(5)
Black	5	(9)	2	(3)	3	(5)	3	(17)
Caucasian	92	(166)	95	(174)	90	(163)	92	(503)
Hispanic	0	(1)	3	(5)	2	(4)	2	(10)
Native American	2	(3)	1	(2)	3	(6)	2	(11)
Unspecified	0	(1)	0	(0)	0	(0)	0	(1)
Number of years as DDD client:*								
Less than 2 years	23	(43)	18	(33)	9	(16)	17	(92)
2 to 5 years	42	(78)	43	(79)	22	(39)	36	(196)
More than 5 years	34	(63)	39	(72)	69	(124)	47	(259)
Current or most recent school program:*								
Special school/facility (segregated)	26	(50)	40	(76)	43	(80)	36	(206)
Special classes (regular school)	64	(122)	47	(90)	28	(52)	46	(264)
Some/all regular academic classes	9	(17)	11	(21)	12	(22)	11	(60)
Never attended school	1	(2)	2	(4)	17	(32)	7	(38)
Always lived at home:*								
Yes	84	(163)	84	(162)	61	(116)	77	(441)
No	16	(31)	16	(30)	39	(73)	23	(134)
Former resident of state institution:*								
Yes	2	(4)	9	(16)	19	(36)	10	(56)
No	98	(184)	91	(171)	81	(150)	90	(505)

a/ "Urban" means living in one of ten Washington counties located within a Standard Metropolitan Statistical Area, as identified in the 1980 Census: Benton, Clark, Franklin, King, Pierce, Snohomish, Spokane, Thurston, Whatcom, and Yakima Counties.

*p < .05

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race 1/. However, the educational and residential histories of clients were significantly different among age groups. There were more older clients who had previously lived away from home, most often in the home of another relative. Younger clients were less likely to have lived in a state institution or to have attended special schools or facilities where they were segregated from non-handicapped students.

TABLE 2.2

FAMILY CHARACTERISTICS
BY AGE GROUP

	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Annual income:*				
Under $10,000	19	26	34	26
$10,000 - 20,000	21	38	42	33
$20,000 - 40,000	50	29	19	33
Over $40,000	10	7	5	8
Family composition:*				
2 parents	80	72	49	67
1 parent	18	24	41	28
Relative/guardian other than parent	2	4	10	5
Parent employment:*				
At least 1 parent works full-time	77	60	32	56
No parent works full-time	23	40	68	44
Parent health:				
At least 1 parent in good health	86	85	81	84
No parent in good health	14	15	19	16
Parent age:*				
At least 1 parent less than 60 years old	94	69	37	67
No parent less than 60 years old	6	31	63	33

* $p < .05$

The families of clients in each age group differed from one another in several respects (Table 2.2). The average family size for the oldest client group was 3.0, which was significantly smaller than the families of the 16-21 and 22-29 age groups (4.0 and 3.7, respectively). Older clients were also much more likely to live in single-parent households, and their parents were more often retired, over 60 years old, and in fair to poor health.

1/ According to recent population statistics (Washington State Data Book: 1983, Office of Financial Management, February 1984) the percentages of Black, Native American, and Hispanic individuals in Group A parallel the total state distribution of these ethnic groups. However, Group A includes a smaller percentage of Asians than in the state population as a whole.

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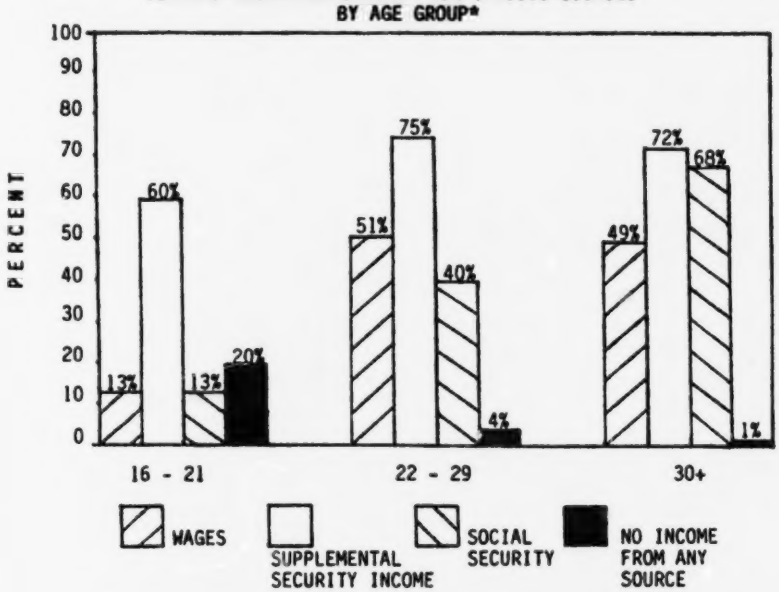
Annual household income, as reported by parents, was significantly less among families of older clients. However, the older clients' contribution to household income appeared to be significantly higher than younger clients. According to DD Specialists' estimates, the average gross monthly income for clients in the 16-21 group was $249, significantly less than the $330 average for clients aged 22-29 and the $360 average for clients over age 30. The primary source of client income was Supplemental Security Income (SSI), a Federal program that distributes monthly checks to aged, disabled, and blind people with limited income assets. Figure 2.1 depicts the percentage of clients receiving income from SSI and other major sources. As illustrated, the percentage of clients without income from any source external to the family decreased significantly in the older age group.

FIGURE 2.1

CLIENTS RECEIVING INCOME FROM VARIOUS SOURCES BY AGE GROUP*



Note. Percentages of reported income within each age group exceed 100% due to incidences of multiple sources of income. Individuals who receive SSI may also receive Social Security benefits and/or have some earned income.

* $p < .05$

The type and extent of developmental disabilities, as documented in DDD case records, indicated that 93 percent of the clients were mentally retarded--with or without accompanying disabilities (Table 2.3). No significant differences were found among age groups in levels of retardation for mentally retarded clients. There was no record of

the level of retardation for nearly one-fifth of the clients reported as mentally retarded. There were proportionally fewer severely and profoundly retarded individuals living with their families than living in DDD community residential facilities. Eighteen percent of all the clients were multiply handicapped, and seven percent had disabilities other than mental retardation. Sixteen percent of the clients used special equipment, most often a wheelchair.

TABLE 2.3

NATURE AND EXTENT OF DEVELOPMENTAL DISABILITY
AS DOCUMENTED IN DDD CASE RECORDS
BY AGE GROUP*

	16-21 (N=186)	22-29 (N=179)	30+ (N=168)	TOTAL (N=533)
Developmental disability:	%	%	%	%
Mental retardation (MR) only	72	76	77	75
MR with another disability	22	16	16	18
Cerebral palsy (without MR)	5	3	2	4
Epilepsy (without MR)	0	3	1	1
Other disability (without MR)	1	2	4	2
	(N=173)	(N=165)	(N=156)	(N=494)
Level of mental retardation: (excluding clients without MR)	%	%	%	%
Borderline a/	28	30	20	26
Mild	20	16	17	18
Moderate	27	21	29	25
Severe	8	12	10	10
Profound	2	4	2	3
Unspecified	16	18	23	19

a/ "The previous American Association on Mental Deficiency classification system included the Borderline category, which was used for individuals who scored between one and two standard deviations below the mean on I.Q. tests. The Borderline level has been dropped from the system." Manual on Terminology and Classification in Mental Retardation. (Ed.) American Association on Mental Deficiency/Special publication No. 2, 1973. However, the Borderline category still occurs on DDD client records.

* No significant differences were found between groups.

Physical, Mental, and Dental Health

Most clients (82% overall) were described as in good or excellent health; less than five percent were described as in poor health. Eighty-two percent of the parents indicated that during the past year the clients' health had stayed the same, 11 percent reported improvement, and 7 percent reported decline. Although one-third of the clients had chronic health conditions (most frequently circulatory problems), about two-thirds of those with chronic health conditions were reported to be in good health. On the other hand, parents reported that 10 percent of the clients had physical health needs that were not being treated. On the average, clients had been seen by a physician three or four times over the previous year; clients who were in poor health or who experienced chronic problems averaged two to five times as many doctor visits as those in better health or without chronic problems.

The incidence of diagnosed mental illness, according to DDD records, was less than five percent. But 21 percent of the clients were reported to have general but unspecified mental health needs that were not being met. Clients in the 16-21 age group were more likely than older clients to be described as having mental health needs that were not being met: 27 percent (ages 16-21) versus 18 percent (ages 22-29 and ages 30+).

The typical client was seen by a dentist twice during the past year. Over three-fourths of the parents reported that clients were receiving adequate dental care and attention. When those not receiving adequate dental care (19%) were asked to explain why not, three-fourths of the parents reported this was due to limited financial resources.

Client Functioning

Over the past decade there has been a trend away from reliance upon general intelligence measures and toward assessment of individuals' actual functional performance in a range of areas. The parent interview included a series of items about client functioning in the following areas: personal care activities (i.e., self-help), independent living activities, communication, social interactions, and risk management (i.e., personal safety). Additional items covered the presence of dangerous and non-dangerous behavior problems. Parents were asked to describe the client's actual performance, rather than to estimate his/her capabilities or motivation.

For each personal care and independent living activity, parents were asked to describe the amount of help the client usually needed to perform the activity: none, some, a lot, or total. Questions regarding communication and social interactions required parents to select the response which best

characterized the client's typical behavior. Risk management and behavior problems were measured by a series of yes/no questions. For each area of client functioning a summary index was constructed from related items. This facilitated the exploration of possible relationships among different functioning areas and other key variables in this study. Table 2.4 describes these performance indices and summarizes results of pertinent analyses. (See Appendix B for a description of each index.)

TABLE 2.4

DESCRIPTION OF INDICES MEASURING CLIENT FUNCTIONING

INDEX	DESCRIPTION	AGE-GROUP DIFFERENCES	POSITIVE (+) OR NEGATIVE (-) CORRELATION WITH KEY ITEMS/INDICES
Personal care skills (Table B.1)	Describes degree of independence in 7 activities, e.g., eating, dressing.	None	Independent living skills (+) Communication skills (+) Risk management skills(+) Need for home supervision (-)
Independent living skills (Table B.2)	Describes degree of independence in 6 activities, e.g., preparing meals, shopping.	None	Personal care skills (+) Communication skills (+) Risk management skills (+) Need for home supervision (-) Need for community supervision (-)
Communication skills (Table B.3)	Describes whether or not client is verbal, able to express self and understand others in his/her communication mode.	None	Personal care skills (+) Independent living skills (+) Risk management skills (+) Need for home supervision (-)
Risk management skills (Table B.4)	Describes client's ability to handle 6 risk situations, e.g., giving name, address, following pedestrian safety.	None	Personal care skills (+) Independent living skills (+) Communication skills (+) Need for home supervision (-) Need for community supervision (-)
Social skills (Table B.5)	Describes appropriateness of client's behavior in public and ability to get along with others.	Significantly higher for 30+ age group*	None
Dangerous behavior problems (Table B.6)	Describes whether or not client harms self, harms others, or destroys property.	None	None
Non-Dangerous behavior problems (Table B.7)	Describes whether or not client has temper tantrums, is deliberately disobedient, or has severe hyperactivity.	None	None

Note. Tables cited above, which list index items and the frequency of responses by age group, appear in Appendix B.

* $p < .05$

The relationships among selected items and indices are summarized in a matrix of Pearson correlation coefficients (Table 2.5). Each coefficient indicates the strength and direction of association between two variables. The matrix provides a convenient means of comparing the strength of relationships between pairs of variables.

TABLE 2.5

INTERCORRELATIONS AMONG KEY ITEMS AND INDICES

	LMR	AGE	PCS	ILS	NSC	NSH	PRE	DBP	NBP	SOC	COM	DEC	RIM
Level of Mental Retardation (LMR)													
Age (AGE)	.08												
Personal Care Skills (PCS)	-.03	.03											
Independent Living Skills (ILS)	-.11	-.04	.62*										
Needs Supervision in Community (NSC)	.00	-.06	-.37*	-.64*									
Needs Supervision at Home (NSH)	.09	-.01	-.54*	-.62*	.52*								
Parent Perceived Restrictiveness (PRE)	.01	-.07	-.39*	-.46*	.44*	.50*							
Dangerous Behavior Problems (DBP)	.02	-.07	-.02	-.12	.12	.17*	.18*						
Non-Dangerous Behavior Problems (NBP)	.00	-.06	.06	-.02	.08	.12	.15*	.39*					
Social Skills (SOC)	.04	.10	.07	.13	-.16*	-.19*	-.21*	-.27*	-.38*				
Communication Skills (COM)	-.04	.10	.45*	.42*	-.27*	-.36*	-.22*	.18*	.34*	.06			
Client Decision Making (DEC)	-.10	.09	.34*	.65*	-.52*	-.49*	-.36*	.02	.18*	.14*	.65*		
Risk Management Skills (RIM)	-.12*	.08	.50*	.65*	-.48*	-.49*	-.35*	.09	.24*	.21*	.85*	.76*	
DDD Support Services Received (DDS)	-.03	-.09	-.27*	-.29*	.22*	.26*	.22*	.20*	.17*	-.12	.24*	.02	.13

Note. A positive coefficient (no sign) indicates that for a pair of variables as one increases in value the other increases, or as one decreases the other decreases. A negative coefficient (-) means that as one of the pair of variables increases the other decreases. The square of a coefficient equals the proportion of variance shared by the pair of variables. For example, the correlation between the risk management skills and the personal care skills is .50, which means that 25% of the variance in risk management may be explained by the variance in personal care skills.

* $p < .001$

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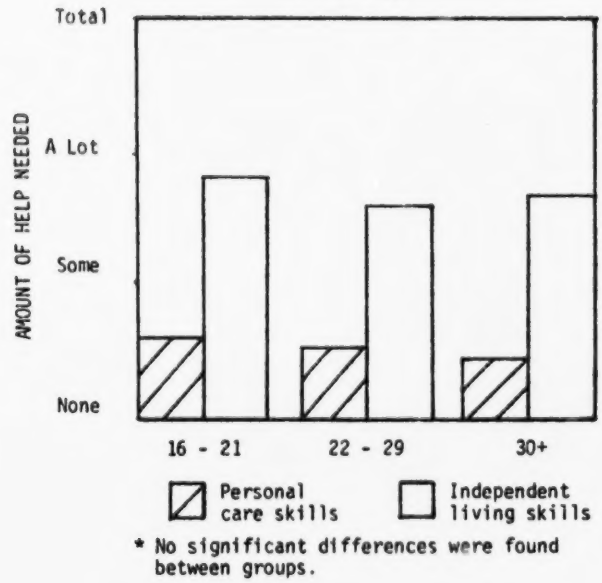
In terms of their personal care the majority of clients were independent in eating, dressing, toileting, bathing, moving about from place to place, and transferring (Table B.1). However, most clients (70%) did require help with personal grooming. Clients needed more help with independent living activities than personal care activities (Figure 2.2). Those independent living activities with which clients usually needed the most help were managing money, shopping, and preparing meals (Table B.2).

FIGURE 2.2

HELP NEEDED WITH DAILY LIVING SKILLS
BY AGE GROUP*



* No significant differences were found between groups.

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Regarding their communication skills, 85 percent of the clients were verbal and understood at least simple sentences. Somewhat fewer clients (69%) were able to use simple sentences to express themselves when communicating outside the family (Table B.3).

At least two-thirds of the clients were described as capable of managing the majority of risk situations--giving personal information, following pedestrian safety rules, knowing what to do in case of fire at home (Table B.4). However, half of the clients did not know how to use a public telephone to call for emergency help. There were high positive correlations between ability to manage risks and performance in three other areas of client functioning: personal care, independent living, and communication. 2/ Clients with more skills in these areas needed less supervision at home and in the community (Table 2.5).

2/ A positive correlation indicates that for a pair of variables as one increases in value the other increases, or as one decreases the other decreases. Conversely, a negative correlation means that as one of the pair of variables increases the other decreases.

Table 2.6 presents data on social abilities and behavior problems. Parents reported that the majority of clients behaved appropriately in public, got along better with family members and external authority figures than with peers, and did not exhibit problem behaviors. Indices were constructed for social skills, dangerous behavior problems and non-dangerous behavior problems (Tables B.5, B.6 and B.7). Overall, clients with more social skills required less supervision at home and in the community, exhibited a lower incidence of behavior problems, and were better at managing risk incidents. Clients in the oldest group had more social skills and fewer behavior problems than the younger clients.

TABLE 2.6

SOCIAL ABILITY AND BEHAVIOR PROBLEMS
BY AGE GROUP

Social Abilities	16-21 %	16-21 n	22-29 %	22-29 n	30+ %	30+ n	TOTAL %	TOTAL n
Behavior with persons outside family:								
Usually/always appropriate	72	(138)	81	(155)	86	(161)	80	(454)
Sometimes appropriate	24	(45)	18	(34)	13	(25)	18	(104)
Seldom/never appropriate	4	(8)	1	(2)	1	(1)	2	(11)
Gets along with family:								
Very well	63	(121)	68	(130)	74	(139)	68	(390)
Adequately	29	(55)	28	(53)	22	(41)	26	(149)
Not very well	8	(16)	4	(8)	4	(8)	6	(32)
Gets along with authorities:*								
Very well	64	(121)	63	(117)	75	(136)	67	(374)
Adequately	30	(57)	35	(66)	19	(35)	28	(158)
Not very well	6	(12)	2	(4)	6	(10)	5	(26)
Gets along with peers:								
Very well	58	(109)	55	(102)	60	(111)	58	(322)
Adequately	33	(62)	35	(65)	31	(57)	33	(184)
Not very well	9	(17)	9	(17)	9	(16)	9	(50)
Behavior Problems a/								
Dangerous behaviors:								
Causing harm to others	11	(21)	7	(13)	5	(9)	8	(43)
Physical self-abuse	11	(21)	8	(16)	6	(11)	8	(48)
Property destruction	11	(21)	8	(15)	8	(16)	9	(52)
None of the above	78	(152)	85	(163)	86	(163)	83	(478)
Non-dangerous behaviors:								
Severe hyperactivity	8	(16)	6	(12)	5	(10)	7	(38)
Temper tantrums	26	(51)	28	(53)	22	(41)	25	(145)
Deliberate disobedience*	33	(65)	21	(40)	20	(38)	25	(143)
None of the above	54	(106)	61	(118)	67	(128)	61	(352)

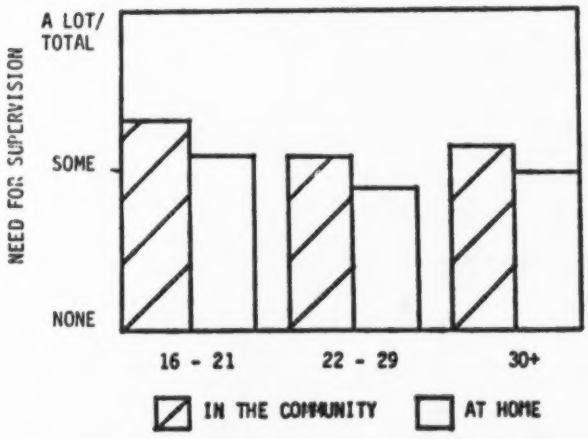
a/ Column percentages exceed 100%, due to incidence of multiple behavior problems.

* p <.05

Parent estimates of client needs for supervision (Figure 2.3) showed a consistently lower need for supervision at home than in the community. High negative correlations were found between need for supervision at home and performance of personal care activities, independent living tasks, risk management and communication (Table 2.5).

FIGURE 2.3

AVERAGE NEED FOR SUPERVISION
BY AGE GROUP*



Note. The response categories "A Lot" and "Total" were combined because reliability tests showed that respondents could not differentiate between them.

* No significant differences were found between groups.

In summary, clients who had high functional abilities in one area tended to have high functional abilities in other areas. For example, persons who could manage risk situations also scored high in personal care, independent living, and communication skills, and required little supervision at home and in the community. Clients scoring low in one area of functioning tended to score low in others as well.

CHAPTER III. CLIENT/FAMILY ACTIVITIES

In addition to reporting the characteristics of clients and their families, the study sought information which would accurately depict their daily lives. Various aspects of the clients' lives were examined, including home and community activities, friendships, exposure to risks, participation in work or training, and use of community services through DDD and other human service providers. Whenever possible, summary indices were constructed to explore possible age-group differences and associations relevant to client/family activities (Table 3.1). This facilitated the identification of relationships between participation in activities and other key variables such as functional abilities.

TABLE 3.1

INDICES DESCRIBING CLIENT/FAMILY ACTIVITIES

INDEX	DESCRIPTION	AGE-GROUP DIFFERENCES	POSITIVE (+) OR NEGATIVE (-) CORRELATION WITH KEY ITEMS/INDICES
Client decision making (Table B.8)	Describes the client's role in making 8 daily decisions, e.g., choosing clothes, having friends over to the house.	None	Independent living skills (+) Communication skills (+) Risk management skills (+) Need for home supervision (-) Need for community supervision (-)
Community activity (Table B.9)	Describes client participation in 6 community activities during the previous month.	Significantly higher for ages 16-21.*	Community mobility (+)
Community mobility (Table B.10)	Describes how many modes of transportation the client uses (e.g., driving, bus, taxi).	Significantly higher for ages 16-21.*	Community activity (+)
Neighborhood accessibility (Table B.11)	Describes proximity to bus, stores, parks, etc.	None	None
Parent perceived restrictiveness (Table B.12)	Describes how much responsibility for the client restricts parental participation in family and community activities or working outside the home.	Significantly higher for ages 16-21*	Independent living skills (-) Need for community supervision (+) Need for home supervision (+)
Family support services (Table B.13)	Describes how many (out of 6) family support services the client/family received from DDD within the past year.	Significantly higher for ages 16-21.*	None

Note. Tables cited above, which list index items and the frequency of responses by age group, appear in Appendix B.

* $p < .05$

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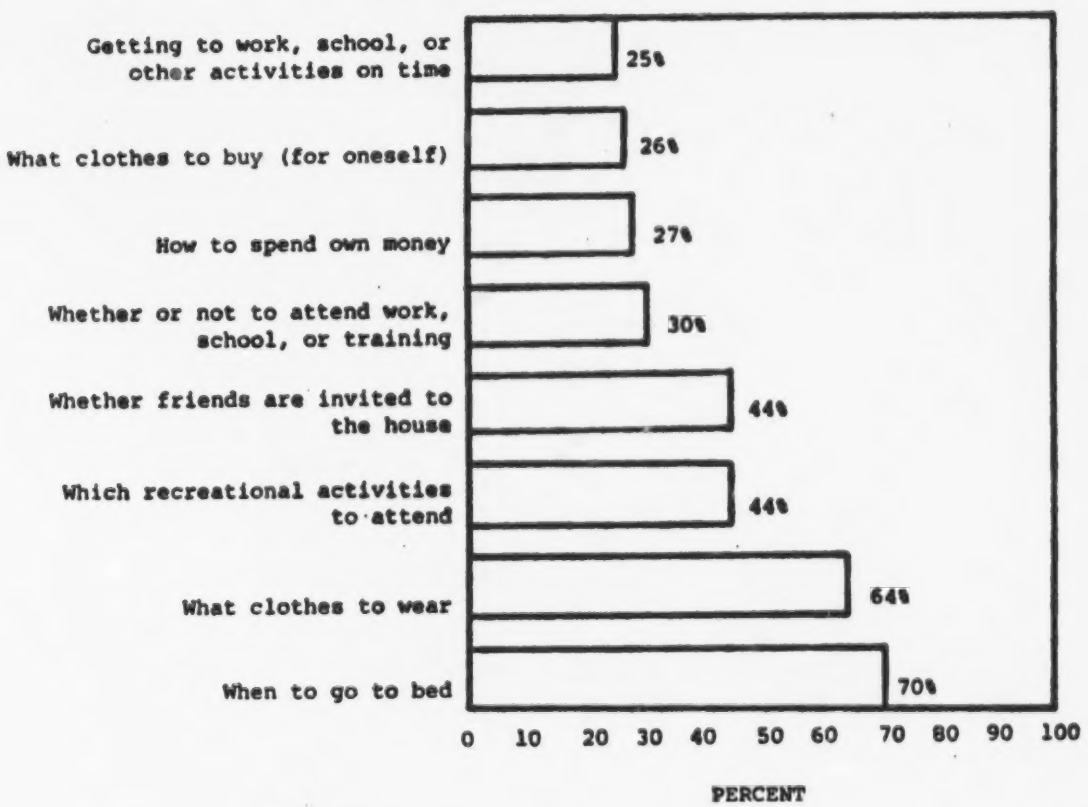
Client Decision Making

In order to measure clients' involvement in decision making at home, parents were asked who was primarily responsible for making decisions about eight daily routines (Figure 3.1). These data indicated that most personal decisions for clients were made by their parents or other family members. There were only two decisions, when to go to bed and what clothes to wear, which over half the parents said were made by the client. An index of responses across all items (Table B.8) revealed that 14 percent of the clients made no decisions about these daily routines. Client decision making was positively correlated with ability to communicate, to manage risks, and to perform independent living skills. Also, client involvement in decision making was significantly less among those with higher needs for home and community supervision (Table 2.5).

FIGURE 3.1

PERCENTAGE OF CLIENTS PRIMARILY RESPONSIBLE FOR MAKING PERSONAL DECISIONS



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Friendship and Social Activities

Families were asked about the client's friends, given the definition "persons other than family members who are special to him/her." Over 80 percent of all clients had one or more friends, and two-thirds had friends of both sexes and of approximately the same age. Clients' friends most often included both handicapped and non-handicapped persons. Whereas about three-fourths of the clients had visited friends or neighbors during the past month, the majority of clients (54%) had not had any friends over to their homes during this time. On a related item parents reported that 45 percent of the clients independently joined group activities and 34 percent joined if encouraged to do so. Those clients who seldom or never participated in group activities (21%) tended to be the same persons who reportedly had no friends.

Parents provided further information about client involvement in community activities--i.e., the extent to which they attended local activities, regardless of whether they went alone or with supervision. At least three-fourths of the clients had gone to restaurants, gone shopping, and visited friends or neighbors during the past month (Table B.9). Out of six community activities, 80 percent of the clients had participated in three or more activities within the last month. Three percent had not participated in any community activities during this time. An index of community activities revealed significant differences between age groups: Clients aged 16-21 were far more likely than older clients to participate in these activities. Level of community activity was not correlated with need for supervision in the community or other indices of client functioning.

Data were also obtained regarding client mobility (use of various means of transportation) and their accessibility to buslines and other community resources. The means of transportation clients used most frequently were walking/using a wheelchair (69%), taking a bus (59%), and riding a bike or moped (28%). Again, it was the youngest client group which used significantly more varied means of transportation than the older groups. At least two-thirds of the clients in every age group lived within walking distance of neighbors, buslines, and grocery stores. No correlations were found between participation in community activities and indices of community mobility and neighborhood accessibility (Tables B.10 and B.11).

Risk and Safety

Parents were asked about incidents within the past year which involved client safety (Table 3.2). The most frequent problem among clients was having money or property stolen; the incidence rate was significantly higher among clients aged 16-21. Problems with drugs or alcohol, which seldom occurred, usually involved excessive drinking.

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During the last year eight percent of respondents had contact with the police involving the client. Several of the contacts reported were not crime-related but involved situations in which the client was lost or missing. Four percent of the families reported police contact(s) about crimes allegedly committed by clients; the most frequent incidents involved disturbing the peace or simple assault, and the client was not typically arrested. Incidents in which clients were victims (2% overall) included physical assault, indecent liberties, theft, robbery, and car accidents. Although police contact was infrequent, it tended to occur more often and be of a more serious nature among younger clients.

TABLE 3.2

CLIENT EXPOSURE TO RISK WITHIN THE PAST YEAR
BY AGE GROUP

	16-21		22-29		30+		TOTAL	
	%	n	%	n	%	n	%	n
Lost or missing:								
Yes	11	(22)	4	(8)	6	(11)	7	(41)
No	89	(172)	96	(183)	94	(178)	93	(533)
Money or property stolen:*								
Yes	19	(36)	10	(20)	9	(16)	13	(72)
No	81	(154)	90	(170)	91	(167)	87	(491)
Problem with drugs or alcohol:								
Yes	2	(4)	1	(2)	2	(3)	2	(9)
No	98	(190)	99	(189)	98	(186)	98	(565)
Sexually exploited:								
Yes-Rape/Statutory rape	1	(1)	1	(2)	0	(0)	1	(3)
Yes-Indecent liberties	3	(6)	0	(0)	1	(1)	1	(7)
No sexual exploitation	96	(186)	99	(188)	99	(187)	98	(561)
Physically assaulted:								
Yes-Injuries did not require professional attention	5	(10)	4	(7)	3	(5)	4	(22)
Yes-Injuries required professional attention	3	(5)	0	(0)	0	(0)	1	(5)
No physical assault	92	(178)	96	(184)	97	(184)	95	(546)
Police contact:								
Yes-As perpetrator of a crime	5	(10)	4	(8)	2	(3)	4	(21)
Yes-As victim	3	(5)	1	(2)	2	(4)	2	(11)
Yes-As neither perpetrator nor victim	3	(5)	3	(5)	2	(3)	2	(13)
No police contact	90	(174)	92	(177)	95	(179)	92	(530)

*p < .05

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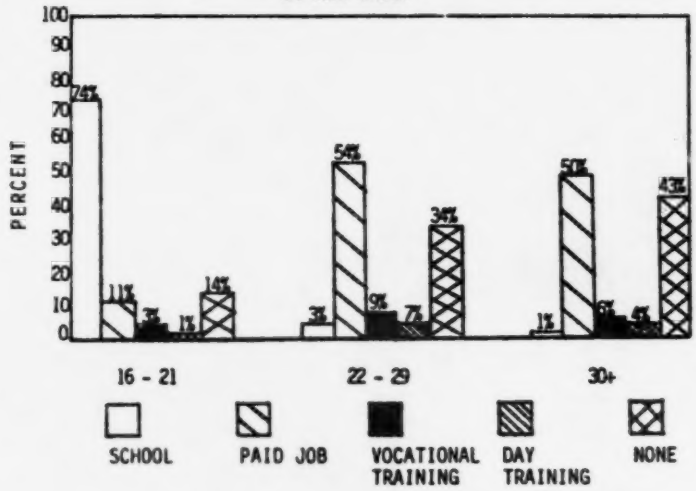
Scheduled Activities

The nature and extent of client participation in scheduled activities--i.e., work, school, and other training programs--differed significantly among age groups (Figure 3.2). Because parents of clients currently attending secondary school (ages 16-21) were not asked if the client also had a paid job or training program outside of school, scheduled activities for this age group may be underreported. Nevertheless, in contrast with older groups, clients in the youngest group were far more likely to participate in at least one scheduled activity on a regular basis. Conversely, there were significantly more clients in the older age groups who did not work or attend any scheduled activities.

FIGURE 3.2

PARTICIPATION IN WORK, SCHOOL, AND TRAINING BY AGE GROUP*



Note. Total of percentages reported within each age group exceeds 100% due to participation in more than one program.

* $p < .05$

Table 3.3 shows the average amount of time spent by clients in each age group who participated in scheduled activities. Because age 21 is the maximum age handicapped students are entitled to a free public education, participation in secondary school is only reported for the youngest group.

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Within this age group 74 percent were currently attending secondary school, 18 percent had already completed 12 years of school or reached age 21, and 7 percent had left school before completing their school program. The average age at which clients left school was 20 for clients in the 16-21 and 22-29 age groups; the question was not asked about clients ages 30 and above.

TABLE 3.3

AVERAGE HOURS PER WEEK SPENT
BY PARTICIPANTS IN SCHEDULED ACTIVITIES
BY AGE GROUP*

	16-21		22-29		30+		TOTAL	
	X̄	n	X̄	n	X̄	n	X̄	n
Attends high school: Hours per week	29	(136)	NOT APPLICABLE				29	(136)
Attends post-high school: Hours per week	40	(1)	9	(6)	6	(2)	12	(9)
Works (paid job): Hours per week	25	(21)	27	(98)	26	(95)	26	(214)
Attends work-training: Hours per week	13	(6)	17	(16)	24	(10)	19	(32)
Attends day training: Hours per week	10	(1)	10	(12)	16	(6)	12	(19)

*No statistical analyses are reported due to the small number of cases involved.

Although the rate of employment differed among age groups, the type of job, wages, and total hours worked were similar. Twelve percent of the clients with paid jobs worked in competitive settings. Those who were competitively employed worked an average of 24 hours per week, with estimated average earnings of $259 per month. On the other hand, clients in non-competitive settings worked an average of 27 hours per week with estimated average earnings of $64 per month.

The total number of hours clients spent in work, school, and training activities combined were computed for each age group. Results indicated that the 16-21 age group spent significantly more hours per week in scheduled activities: Weekly averages dropped from 24 (ages 16-21) to 16 (ages

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22-29), to 15 hours (ages 30+). Overall, 48 percent of the clients spent at least 25 hours per week in scheduled activities, 20 percent spent 1 to 24 hours per week, and 32 percent spent no time in scheduled activities (Table B.14). 3/

Consistent with these findings, reports from DD Specialists indicated that significantly more clients ages 16-21 were receiving formal training in selected skill areas (Table 3.4). "Formal training" was defined as train-

TABLE 3.4

CLIENTS CURRENTLY RECEIVING FORMAL TRAINING
(AS REPORTED BY DD SPECIALISTS)
BY AGE GROUP

	16-21 (N=190) %	22-29 (N=191) %	30+ (N=188) %	TOTAL (N=569) %
Personal care:*				
Yes	31	7	6	14
No/don't know	69	93	94	86
Community living:* (domestic tasks, money management)				
Yes	36	9	7	18
No/don't know	64	91	93	82
Using community resources:* (shopping, telephone, transit)				
Yes	31	10	10	17
No/don't know	69	90	90	83
Speech/language:*				
Yes	34	3	4	13
No/don't know	66	97	96	87
Social interaction:*				
Yes	44	19	12	25
No/don't know	56	81	88	75
Behavior management:*				
Yes	25	14	12	17
No/don't know	75	86	88	83
Vocational/prevocational:				
Yes	47	56	46	50
No/don't know	53	44	54	50

* $p < .05$

3/ "Habilitation Standards to House Bill 270" (Division of Developmental Disabilities, November 1983) states that "...every eligible person will have access to at least five hours of habilitation per day, five days a week, away from where they live." Habilitative services are defined as "employment, education, vocational habilitation, therapy and related services," which corresponds with the "scheduled activities" discussed in this report.

ing provided by paid staff, including school-provided training. For every area except vocational/prevocational training, there were significantly more clients in the youngest group receiving training than in the older groups. At least one-half of all clients received training in one or more skill areas, yet there were significantly more clients aged 30 and above who received no formal training (50%) than in the younger groups (37%). The amount of formal training clients received was not significantly correlated with personal care skills or other measures of client functioning. Despite age-group differences in the extent of training received, the focus of training was generally similar across age groups.

An analysis was performed to determine if clients with dangerous and/or non-dangerous behavior problems had received behavior management training during the previous year. Clients with behavior problems were far more likely than the general client population to be receiving behavior management training. In the youngest group over one-half of the clients with dangerous behavior problems and one-third of those with non-dangerous behavior problems were receiving behavior management training. The reverse was true for older age groups: Just over one-third of the clients with dangerous behavior problems and 70 percent of those with non-dangerous behavior problems were receiving such training.

Supports for the Family

To gain insights about needs and resources for family support, parents were asked a series of questions about time spent away from the client during the past year (Table 3.5). About three-fourths of the families reported spending evenings out without the client during the past year. On the other hand, just over half said they had taken an overnight trip without the client during this period. Whereas 82 percent of all the families reported having someone outside the household to care for the client in an emergency, 18 percent had no one. Almost half the families (42%) reported that someone was available to care for the client as long as necessary.

TABLE 3.5

FAMILY TIME AWAY FROM THE CLIENT DURING THE PAST YEAR
BY AGE GROUP

	16-21		22-29		30+		TOTAL	
	%	n	%	n	%	n	%	n
Take overnight trips without client:*								
Yes	65	(126)	51	(98)	44	(84)	54	(308)
No	35	(68)	49	(94)	56	(105)	46	(267)
During this time, the client:								
Stays alone or with friends	14	(18)	26	(25)	25	(21)	21	(64)
Is supervised	71	(89)	69	(68)	69	(58)	70	(215)
Goes to a special facility	15	(19)	5	(5)	6	(5)	9	(29)
Spend evenings without client:*								
Yes	88	(170)	82	(158)	64	(120)	78	(448)
No	12	(24)	18	(34)	36	(69)	22	(127)
During this time, the client:								
Stays alone or with friends	49	(83)	58	(92)	65	(77)	56	(252)
Is supervised	51	(86)	42	(66)	34	(41)	43	(193)
Goes to a special facility	1	(1)	0	(0)	0	(0)	0	(1)
Have someone to care for client in an emergency:								
Yes - as long as needed	38	(75)	44	(84)	44	(83)	42	(242)
Yes - for up to 6 weeks	31	(60)	26	(49)	22	(41)	26	(150)
Yes - for up to 24 hours	7	(13)	12	(24)	10	(18)	10	(55)
Yes - don't know how long	3	(5)	3	(6)	6	(12)	4	(23)
No/don't know	22	(42)	15	(29)	18	(35)	18	(106)

* $p < .05$

Families were also asked how much their responsibility for the client restricted them in each of the following ways: participation in activities with other family members, pursuit of other interests, and working outside the home. On each of these items over half the parents reported feeling some or a lot of restriction. Analysis of responses across all three items revealed that 27 percent of the families felt no restrictions whatsoever, 12 percent felt very restricted in every area, with the majority (61%) between the two extremes. These items were used to create an index of perceived restrictiveness, and an analysis of variance indicated that the families of the youngest group perceived themselves to be more restricted than families of the two older groups (Table B.12). Perceived restrictiveness was significantly and positively associated with clients' need for supervision at home and in the community, need for more DDD support services and incidence of behavior problems. Parents of clients with fewer skills in personal care, independent living, and social interactions felt more restricted (Table 2.5).

Involvement with DDD

Parents were asked several questions about their involvement with DDD (Table 3.6). About three-fourths of the families reported that their developmentally disabled relative had an assigned DD Specialist. Excluding those without a DD Specialist, most families knew the DD Specialist's name, had been in contact with DDD at least once in the past six months, and described the information or assistance received as good or excellent.

TABLE 3.6

PARENT REPORTS OF INVOLVEMENT WITH DDD
BY AGE GROUP

	16-21 (N=195) %	22-29 (N=192) %	30+ (N=189) %	TOTAL (N=576) %
Have a DD Specialist assigned to them:				
Yes	83	78	70	77
No/don't know	17	22	30	23
	(N=162)	(N=149)	(N=134)	(N=445)
Of those with a DD Specialist, know name of current DD Specialist:*	%	%	%	%
Yes	86	70	67	75
No	14	30	33	25
Last contact with DD Specialist:*				
1984	76	50	51	60
1983	16	24	25	22
1982 or earlier	6	13	10	10
Don't know	2	13	13	9
Contacts with DDD in past 6 months:*				
None	20	29	32	26
1 or 2 times	42	44	46	44
3 or more times	38	27	23	30
Quality of information/assistance from DD Specialist:				
Excellent	30	28	30	29
Good	34	30	36	33
Fair	23	17	13	18
Poor	7	13	10	10
Don't know	6	13	10	9
	(N=195)	(N=192)	(N=189)	(N=576)
DDD family support services received within past year:*	%	%	%	%
At least one--needed no more	18	10	9	13
At least one--needed more	25	9	9	14
None--needed none	25	46	45	38
None--needed at least one	32	34	36	34

* $p < .05$

As shown in Table 3.6, 27 percent of all families interviewed had received one or more DDD family support services (e.g., respite care, therapy, attendant care) within the past year. With few exceptions, families receiving support services from DDD found them to be adequate (Table B.15). On the other hand, 73 percent had received no family support services during this time. Over half of those who did not receive any support services (38% overall) reported no need for them.

Regardless of whether services were currently being provided, 48 percent of the families reported a need for one or more family support services. Table 3.7 shows the types of family support services families were more likely to need.

TABLE 3.7

FAMILIES REPORTING A NEED FOR
FAMILY SUPPORT SERVICES
BY AGE GROUP

	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Therapy*	42	32	30	35
Counseling*	21	14	14	16
Respite care	12	15	13	14
Attendant care	9	6	8	8
Special equipment	8	5	8	7
Money for remodeling	7	8	3	6

* $p < .05$

Age-group comparisons showed that families of clients aged 16-21 were more likely to know their DD Specialist and to have had more frequent and more recent contact with DDD Field Services staff. There were also significantly more families of clients in this age group who were currently receiving DDD family support services and who reported a need for such services.

CHAPTER IV. CLIENT STATUS--CURRENT AND FUTURE

Parents and DD Specialists were asked their opinions about the client's current status, future expectations they had concerning the clients, and what plans and provisions had been made regarding the client's future. The opening section summarizes their opinions concerning the current status of clients. The next section describes the future plans and provisions that have been made for clients and how these relate to the clients' current circumstances. The final sections address issues of special interest for clients in the youngest and oldest age groups.

Current Status of Clients

DD Specialists were asked their opinions about the client's current home situation and integration within the family. They reported that most clients were given opportunities to contribute to the family as a whole (65%) and got along adequately with other family members (80%). DD Specialists felt that about half the clients were treated as adults and were encouraged to assume increasing responsibility and independence. In the majority of instances (55%), they believed that the client's current living situation was beneficial for the client and for other members of the family. Analysis of these responses by age group revealed no significant differences.

DD Specialists were asked whether or not they were concerned about the client's residential setting, job or training program, community integration and health (Table 4.1). Given an array of 15 possible concerns, DD Specialists reported no concerns whatsoever for approximately 40 percent of the clients. Among the most common concerns were that clients had no job or training program, were isolated from their peers, needed training in social and community living skills, or lived in an overprotective environment. Comparisons across age groups revealed consistently more concerns about young adults (ages 22-29) and fewer concerns about youths (ages 16-21). Yet, the nature of concerns was similar for all clients.

At the conclusion of the interview parents were given an opportunity to express additional concerns about the client's current or future circumstances. Three-fourths expressed no additional concerns. Of the one-fourth with additional concerns, parents of clients aged 16-21 had the most concerns and parents of clients aged 22-29 had the fewest. Again, the topics of concern were similar regardless of clients' ages. Seven percent of all parents expressed concerns about the lack or inappropriateness of a job or training program for the client; other common concerns included what would happen to the client when the parents die (5%) and finding an appropriate residential alternative for the client (5%). Additionally, about half of the parents were interested in receiving information about education and vocational programs (63%), alternative living situations (58%), and financial planning (49%).

TABLE 4.1

SPECIFIC CONCERNS REPORTED BY DD SPECIALISTS
BY AGE GROUP*

	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Residential Concerns:				
Unsatisfactory home location	1	2	1	1
Overprotective environment	10	34	24	22
Poor interpersonal relations	8	11	7	9
Behavior problems at home	9	8	4	7
NO RESIDENTIAL CONCERNS	73	57	63	64
Concerns About Work, School or Training:				
No job or habilitation program	17	26	32	25
Unsatisfactory location	1	2	1	1
Job/program inappropriate	6	12	4	8
Poor interpersonal relations	4	3	1	3
Behavior problems at job/program	5	4	3	4
NO SUCH CONCERNS	71	59	60	64
Concerns About Community Integration:				
Isolation from peers	16	30	29	25
Limited contact with non-handicapped persons	9	14	11	11
Need for social skills training	26	28	21	25
Behavior problems in public	8	4	5	6
NO SUCH CONCERNS	62	52	58	57
Concerns About Client Health:				
Physical health needs attention	8	10	7	8
Mental health needs attention	6	13	9	9
NO HEALTH CONCERNS	87	78	82	82

Note. Percentages within each category exceeded 100% due to incidence of multiple concerns.

* No statistical analyses are reported due to low response rates.

Goals and Preferences for the Client's Future

Parents were asked about their immediate and long-range goals and preferences for the client, given an array of vocational and residential alternatives (Table 4.2). Parents of clients in the two younger groups were asked what type of work or structured program they considered most appropriate for the client within the next two years (short-term). About two-thirds of the parents indicated that a sheltered work environment would be most appropriate, and about 10 percent did not know. Other short-term goals included competitive employment, college coursework, and activity programs.

TABLE 4.2

VOCATIONAL GOALS AND RESIDENTIAL PREFERENCES FOR THE CLIENT'S FUTURE BY AGE GROUP

	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Short-term vocational goal: (within two years)				
Competitive employment	10	13		
Sheltered work/training	63	66		
Day program	7	5		
Post-high school	6	4	NOT ASKED	
Other	4	3		
Don't know	10	9		
Long-range vocational goal:* (beyond two years)				
Competitive employment	32	29	16	26
Sheltered work/training	61	61	70	64
Day program	5	7	11	8
Other	1	4	3	2
Preferred permanent residential setting:*				
Family home (status quo)	31	56	67	51
Independent living	24	18	11	18
Supervised group living	35	18	17	23
Specialized group living	9	5	2	5
Friend/relative's home	0	3	3	2

* $p < .05$

The majority of parents (64%) thought that a sheltered work environment was the most suitable long-range vocational goal for the client. However, parents of clients under 29 years of age were more likely to consider competitive work most suitable. Comparison of long-term vocational goals with the client's current vocational program indicated that 73 percent of the parents of employed clients considered the client's present type of employment (either competitive or non-competitive) appropriate as a long-term goal. The families of clients who were not employed most often indicated sheltered employment as their long-term goal (42%) or said they did not know (25%).

For the 523 clients who were not competitively employed at the time, DD Specialists were asked their opinions of each client's potential for competitive employment. DD Specialists estimated that 24 percent (128) of these clients had moderate to good potential, 37 percent (192) had some potential, and 29 percent (154) had little or no potential; no estimates were given for 9 percent of this group.

TABLE 4.3

PARENTS' LONG-RANGE VOCATIONAL GOALS FOR CLIENTS COMPARED TO DD SPECIALISTS' OPINIONS OF THE CLIENTS' POTENTIAL FOR COMPETITIVE EMPLOYMENT

Parent's long range vocational goal:	DD Specialist's Opinion of the Client's Potential for Competitive Employment: Moderate/Good %	n	Some %	n	Little/None %	n
Competitive job	38	(49)	3	(5)	3	(5)
Sheltered work	41	(52)	58	(112)	57	(88)
Day program	3	(4)	4	(8)	11	(17)
Other	1	(1)	1	(2)	4	(6)
Don't know	17	(22)	18	(34)	25	(38)

Note. These data pertain only to those clients who were not competitively employed at the time.

Families' long-range vocational goals for the clients were contrasted with DD Specialists' estimates of client job potential to determine the extent of agreement between the two (Table 4.3). For the most part, parents' expectations appeared to be consistent with the DD Specialists' estimates of client job potential. Few families appeared to have long-range vocational goals which exceeded the clients' potential as judged by the DD Specialist: Less than four percent of the clients said to have little job potential were expected to have competitive jobs in the future. On the other hand, competitive employment was indicated as a long-range vocational goal for 38 percent of the clients characterized as having good job potential. Age-group comparisons showed that the expectations of DD Specialists and parents were significantly lower for older clients.

Twenty-six percent of the families anticipated that the client would move away from home within the next two years. The percentage of families who expected a move dropped significantly across age groups: 45 percent (ages 16-21), 22 percent (ages 22-29), and 12 percent (ages 30+). The most common reasons given for the anticipated move were availability of an appropriate residential setting (23%), or because the client was ready to assume more independence (21%), or simply that the client wanted to move out (12%). Those who did not expect the client to move out within two years most often foresaw such a move only when the parent(s) became seriously ill or died.

There were significant differences among age groups concerning parents' preferences for a permanent residential setting for the client (Table 4.2). Most families of clients over age 21 preferred that the client continue living with them, whereas the families of younger clients most often preferred supervised group living situations.

Family residential preferences were analyzed on the basis of their relative degree of supervision by computing correlation coefficients (r). Parents who preferred more closely supervised residential settings felt more restricted by the clients' presence at home (r=.25) and reported greater need for client supervision at home (r=.26) and in the community (r=.29). Parents who preferred more independent residential settings had children with higher performance in independent living skills (r=.33), decision making (r=.32) and risk management (r=.25).

Arrangements for the Client's Future

Families were asked about the type and extent of arrangements already made for the client's future (Table 4.4). Overall, 68 percent of the families had made financial arrangements. The most common financial arrangement was provision in the parent's will. About two-thirds of the families had made arrangements for someone to assume responsibility for the client after the death of the parent(s). Parents who were 60 years old or more, or in fair to poor health, were no more likely to have made financial or sponsorship arrangements for their children.

TABLE 4.4

ARRANGEMENTS FOR THE CLIENT'S FUTURE
BY AGE GROUP

	16-21 (N=195) %	22-29 (N=192) %	30+ (N=189) %	TOTAL (N=570) %
Financial arrangements: a/				
Inheritance	44	50	54	49
Savings	23	33	36	31
Life insurance	27	27	20	25
Trust fund	20	21	18	20
Property	9	8	14	11
Other	8	5	12	8
None	38	30	27	32
Arrangements for responsibility of client after death of parent(s):*				
Designated guardian	40	32	28	34
Sponsor/advocate	17	31	38	29
Other	2	3	0	2
None	40	34	34	36

a/ Column percentages exceed 100%, due to incidence of multiple financial arrangements.

* $p < .05$

Special Issues: Clients Aged 16 through 21

Preparations for the clients' transition to adult roles and independent living

Seventy-three percent of the clients in this age group were attending school. Eighty-eight percent of the students were receiving work-related training through the school; in most cases the parents considered this training useful in preparing for adult living. One-third of the students were receiving help in planning what they would do after leaving school, often through the school (68%) or DDD (21%). The majority (60%) of parents of clients still in school reported there was school-family cooperation in planning the client's transition to adult living.

About one-fourth of the clients in this age group were not attending secondary school. Most often those who left school had completed 12 years of schooling (48%), or they had reached age 21 (24%); however, 28 percent of the non-students left before completing their school program. About half of the non-students (53%) either had a job or were participating in a work-related training program, and another 12 percent were looking for employment. Fifty-one percent of the parents of non-students said the client's weekly schedule of activities provided a normal routine. Somewhat fewer (39%) thought that the client was satisfied with his/her current job or training program.

Likelihood that they will remain at home

According to parent reports, nearly half of the clients in this age group were expected to move from home within the next two years. The residential settings preferred most often by parents were supervised group living (34%) and continued family living (31%). In contrast, parents felt that the clients were more likely to prefer continued family living (44%) or independent living (20%).

Special Issues: Clients Aged 30 and Above

Provisions made for the client's future

About half of the families of clients aged 30 or over consisted of a single parent, and half of the parent(s) were either 60 or more, or in fair to poor health. Almost one-third of these families had not made any financial or sponsorship arrangements for the client's future. In constrast with other age groups, these families received the least DDD support services, although less than half (45%) reported a need for such services.

Only 11 percent expected the client to move out in the next two years and then only if they could find a suitable living situation for the client. Eighty percent did not expect the client to move out in the next few years, and nine percent did not know. About two-thirds of these families indicated a preference for the client to continue living at home as long as possible. When asked where they thought the client would live when they could no longer care for him/her, the most frequent responses were a friend or relative's home (36%), supervised group living (28%), and independent living (12%). Thirteen percent expected the client to move to a specialized facility or institution for the mentally retarded, and 11 percent did not know.

APPENDIX A

METHODOLOGY
FOR GROUP A

Sample Selection

Early in the study a computerized population data file was created which included demographic information on all DDD Field Services clients in Washington State as of November 15, 1983. This data file was used to draw a statewide random sample of 250 clients for each age group. Due to inaccurate client records that necessitated drawing replacements, actual sample sizes ranged from 243 to 251. These sample sizes were sufficient to generalize study findings to the population with a margin of error of approximately seven percent at the 95 percent confidence level.

When each sample was selected, information from the DDD population file was used to verify that the sample was representative of the population from which it was drawn. Comparison of sample and population distributions by sex, developmental disability, level of mental retardation, and urban or non-urban status showed that each sample was clearly representative. The age distribution for the sample of clients aged 30 and above was also found to approximate the statewide distribution of clients over 30 years old.

Data Collection

Data collection for Group A utilized information from three sources. Each client's name, address, age, sex, DD Specialist, closest relative or guardian, and living situation was obtained from the DDD population file. Information on the clients' current functional abilities and needed supports, daily routines, living environment, sources of formal and informal support, and future needs and goals was obtained through telephone interviews with relatives or guardians. Corroborating information was requested from the DD Specialist assigned to each client.

The relative/guardian interview consisted of over 300 items, which took approximately one hour to administer. The mail survey sent to DD Specialists included 70 to 80 items, which required 20-25 minutes to complete. Data collection instruments for each sample covered much of the same general material, as well as unique items applicable to particular subgroups. Many questionnaire items were similar to those from earlier studies of DDD clients in Washington, which facilitated comparisons of client characteristics across residential settings. Preliminary questionnaires were pretested and reviewed by a DDD advisory group. Instruments were subsequently revised, based on reviewer comments and pretest results.

The interview team, five experienced telephone interviewers, received several days of training and orientation prior to data collection. This included review of the study objectives, background information about developmentally disabled populations and programs, and current issues surrounding services for developmentally disabled adults. Each questionnaire was thoroughly reviewed, with detailed instructions given on how to ask, record, and code each item.

At the conclusion of training, the closest relative or guardian of each client in the sample was contacted and requested to participate in a voluntary telephone interview. The interview response rates for each age group are presented below in Table A.1.

TABLE A.1

INTERVIEW RESPONSE RATES
BY AGE GROUP

	16-21 (N=243) %	22-29 (N=245) %	30+ (N=250) %	TOTAL (N=738) %
Completed interviews	80	78	76	78
Refusals	6	6	16	10
Could not be contacted	14	16	8	12

Reliability

Data collection procedures incorporated several reliability checks, particularly for the first and most complex effort--the telephone interviews. The following procedures were used to ensure maximum consistency in measurement:

(1) Interviewer training sessions emphasized the achievement of acceptable levels of inter-rater reliability prior to beginning the telephone interviews. Through interviews conducted with surrogate respondents, each interviewer recorded responses and compared results with the group until consensus on the appropriate frame of reference was achieved. After 25 interviews were completed, results were analyzed. New response categories and decision rules were added, as necessary. Interviews with subsequent samples were monitored routinely to identify and resolve problems with new items.

(2) Test-retest reliability was measured at the end of data collection for the first sample. The questionnaire was divided into six parts, and one part was readministered to 30 respondents picked at random from the original sample. Retest items were administered by the original interviewer, within two weeks of the initial interview. Discrepancies between first and second interviews were examined and unreliable items removed from further analysis.

(3) Interviewers rated each respondent at the close of the interview in terms of attentiveness, comprehension and overall reliability. Respondents with "poor" ratings in two or more areas were to be considered unreliable and removed from further analysis. However, none met this criterion.

To minimize intrusion on Field Services staff, no formal reliability tests were performed on data obtained from DD Specialists.

Data Analysis

The data were keyed onto tape at DSHS headquarters in Olympia. The raw data were then run through range and logic edit programs and corrected before system files were created using SPSS-X (Statistical Package for the Social Sciences, Version X). The DDD Field Services data, relative/guardian survey data and DD Specialist survey data for Group A were then merged into one master file to facilitate comparative analyses among the three age groups.

Some data reduction was performed by constructing summary indices for related item subsets. Two types of indices were created. The first type, which will be referred to as "count indices," were made up of dichotomized variables (e.g., yes = 1, no/don't know = 0). These indices were constructed by counting the number of "yes" responses (value = 1) across all items in the index for each case. The maximum index score is equal to the number of items in the index; the lowest index score is zero. The count indices included communication skills, risk management skills, dangerous behavior problems, non-dangerous behavior problems, decision making, community activity, community mobility, neighborhood accessibility, and family support services provided by DDD.

The second type of index was made up of items with more than two response values (e.g., never = 1, sometimes = 2, often = 3). In this case the response values were summed across all items in the index for each case, with item means substituted for items with missing values. For this type of index the maximum index score is equal to the sum of the highest values of all items in the index. The summed indices were personal care skills, independent living skills, social skills, and parent perceived restrictiveness.

A reliability analysis of index components was performed by computing Cronbach's alpha test for internal homogeneity. This is a standard test of internal consistency among items used to construct an index. 4/ When alpha is squared it becomes the coefficient of reliability which equals the proportion of variance shared by all items used to construct the index. It was decided that if items shared at least 49 percent of the total variance that the internal consistency of the index was sufficient for the purposes of this study. Thus indices with an alpha of .70 or greater were used in analysis. All items used to construct each of the indices discussed in the text are presented in Appendix B.

The primary mode of data analysis was descriptive. Frequency distributions, means, and medians were generated across all data items. Tests of statistical significance between groups were performed on all the data reported in the tables. Data reported in percentage format were evaluated with the Chi-square statistic; data reported as averages were subject to a one-way analysis of variance and were evaluated with the F statistic. Relationships among related items and indices were analyzed by computing Pearson correlation coefficients to determine the direction and strength of associations.

4/ Cronbach, L. "Coefficient Alpha and the Internal Structure of Tests". Psycometrika, XVI. 1951, pp. 297-344.

APPENDIX B

TABLES

Tables B.1 through B.13 present information about each of the summary indices described in Chapter II and Chapter III: the items included in each index, the frequency of responses by age group, and other relevant statistics.

Tables B.14 and B.15 give the frequency of responses to sets of items mentioned briefly in the text.

TABLE B.1
PERSONAL CARE SKILLS INDEX

AMOUNT OF HELP NEEDED WITH PERSONAL CARE ACTIVITIES	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Eating:				
4-None	79	83	86	83
3-Some	14	8	9	10
2-A lot	4	5	2	4
1-Total	3	5	3	3
0-Don't know	0	0	0	0
Dressing:				
4-None	66	75	72	71
3-Some	20	12	17	16
2-A lot	5	6	6	6
1-Total	9	7	5	7
0-Don't know	0	0	0	0
Using toilet:				
4-None	76	78	83	79
3-Some	14	9	8	10
2-A lot	4	3	5	4
1-Total	6	10	4	7
0-Don't know	0	0	0	0
Bathing:				
4-None	56	54	55	55
3-Some	22	26	22	24
2-A lot	11	7	11	9
1-Total	11	13	12	12
0-Don't know	0	0	0	0
Grooming:				
4-None	20	37	34	30
3-Some	54	42	44	47
2-A lot	15	9	12	12
1-Total	11	12	10	11
0-Don't know	0	0	0	0
Walking/moving about:				
4-None	89	86	91	89
3-Some	5	7	4	5
2-A lot	1	1	4	2
1-Total	5	6	1	4
0-Don't know	0	0	0	0
Transferring:				
4-None	90	90	92	91
3-Some	1	4	2	2
2-A lot	2	0	3	2
1-Total	7	6	3	5
0-Don't know	0	0	0	0

No. of cases: 577
No. of items: 7
Range of values: 7 = minimum
28 = maximum

$\bar{X}$ Scores: 24.3 (16-21)
24.6 (22-29)
24.9 (30+)
24.6 (Total)
Standard deviation: 5.0 (Total)

TABLE B.2

INDEPENDENT LIVING SKILLS INDEX

AMOUNT OF HELP NEEDED WITH INDEPENDENT LIVING ACTIVITIES	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Preparing meals:				
4-None	7	15	14	12
3-Some	23	29	22	25
2-A lot	35	26	22	28
1-Total	35	30	41	35
0-Don't know	0	0	2	1
Performing household tasks:				
4-None	31	39	45	38
3-Some	38	39	30	35
2-A lot	19	11	10	13
1-Total	12	12	14	12
0-Don't know	0	0	2	1
Shopping:				
4-None	7	12	13	10
3-Some	20	27	15	21
2-A lot	35	29	28	31
1-Total	37	32	43	37
0-Don't know	0	1	1	1
Using telephone:				
4-None	42	44	36	41
3-Some	14	17	17	16
2-A lot	11	14	14	13
1-Total	31	24	32	29
0-Don't know	1	1	0	1
Using transportation:				
4-None	18	29	38	28
3-Some	25	20	13	19
2-A lot	20	23	17	20
1-Total	34	27	28	30
0-Don't know	3	1	4	3
Managing money:				
4-None	2	5	4	4
3-Some	8	11	13	10
2-A lot	40	36	25	34
1-Total	50	48	58	52
0-Don't know	0	0	0	0

No. of cases: 577
No. of items: 6
Range of values: 6 = minimum
24 = maximum

$\bar{X}$ Scores: 13.3 (16-21)
14.5 (22-29)
13.7 (30+)
13.8 (Total)

Standard deviation: 4.7 (Total)

TABLE B.3

COMMUNICATION SKILLS INDEX

COMMUNICATION SKILLS	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
How client communicates with others:				
1-Verbal	82	87	86	85
0-Non-verbal	18	13	13	15
0-Don't know	0	0	0	0
Ability to understand:				
1-Understands simple sentences	85	85	89	86
0-Does not understand simple sentences	15	12	10	12
0-Don't know	0	2	1	1
Ability to express self outside family:				
1-Uses simple sentences	64	72	70	69
0-Does not use simple sentences	36	27	28	30
0-Don't know	0	0	2	1

No. of cases: 577
No. of items: 3
Range of values: 0 = minimum
3 = maximum

$\bar{X}$ Scores: 2.8 (16-21)
2.8 (22-29)
2.8 (30+)
2.8 (Total)
Standard deviation: .4 (Total)

TABLE B.4

RISK MANAGEMENT SKILLS INDEX

CLIENT KNOWS	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Name:				
1-Yes	89	93	91	91
0-No	10	6	8	8
0-Don't know	0	1	1	1
Address:				
1-Yes	85	88	84	86
0-No	15	10	13	13
0-Don't know	0	1	3	1
Phone number:				
1-Yes	84	84	83	84
0-No	4	12	14	14
0-Don't know	1	3	4	3
How to use public phone:				
1-Yes	40	44	37	40
0-No	49	48	56	51
0-Don't know	11	7	7	8
Pedestrian rules:				
1-Yes	68	74	73	72
0-No	26	22	20	23
0-Don't know	6	3	7	5
What to do if fire at home:				
1-Yes	68	67	73	69
0-No	22	23	18	21
0-Don't know	10	10	9	10

No. of cases: 577
No. of items: 6
Range of values: 0 = minimum
6 = maximum

$\bar{X}$ Scores: 4.3 (16-21)
4.5 (22-29)
4.4 (30+)
4.4 (Total)
Standard deviation: 1.8 (Total)

TABLE B.5

SOCIAL SKILLS INDEX

SOCIAL BEHAVIOR	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Behavior is socially appropriate:				
3-Usually	71	81	85	80
2-Sometimes	23	18	13	18
1-Seldom	4	1	0	2
0-Don't know	2	0	2	1
Gets along with family:				
3-Very well	62	68	73	68
2-Adequately	28	28	22	26
1-Not very well	8	4	4	6
0-Don't know	2	0	1	1
Gets along with authorities:				
3-Very well	62	61	72	65
2-Adequately	29	34	18	27
1-Not very well	6	2	5	5
0-Don't know	3	3	5	3
Gets along with peers:				
3-Very well	56	53	58	56
2-Adequately	32	34	30	32
1-Not very well	9	9	8	9
0-Don't know	4	4	3	4

No. of cases: 577
No. of items: 4
Range of values: 4 = minimum
12 = maximum

$\bar{X}$ Scores: 10.1 (16-21)
10.4 (22-29)
10.5 (30+)
10.3 (Total)
Standard deviation: 1.9 (Total)

TABLE B.6

DANGEROUS BEHAVIOR PROBLEMS INDEX

CLIENT HAS A SIGNIFICANT BEHAVIOR PROBLEM	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Causing physical harm to others:				
1-Yes	11	7	5	8
0-No	89	93	94	92
0-Don't know	0	0	2	0
Causing physical harm to self:				
1-Yes	11	8	6	8
0-No	88	92	94	91
0-Don't know	1	0	0	0
Destroying property:				
1-Yes	11	8	8	9
0-No	89	92	92	91
0-Don't know	0	0	0	0

No. of cases: 577
No. of items: 3
Range of values: 0 = minimum
3 = maximum

$\bar{X}$ Scores: .3 (16-21)
.2 (22-29)
.2 (30+)
.2 (Total)

Standard deviation: .6 (Total)

TABLE B.7

NON-DANGEROUS BEHAVIOR PROBLEMS INDEX

CLIENT HAS A SIGNIFICANT BEHAVIOR PROBLEM	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Severe hyperactivity:				
1-Yes	8	6	5	7
0-No	91	92	93	92
0-Don't know	1	3	2	2
Temper tantrums:				
1-Yes	26	28	22	25
0-No	73	71	78	74
0-Don't know	0	1	0	0
Deliberate disobedience:				
1-Yes	33	21	20	25
0-No	66	78	78	74
0-Don't know	0	1	2	1

No. of cases: 577
No. of items: 3
Range of values: 0 = minimum
3 = maximum

$\bar{X}$ Scores: .7 (16-21)
.5 (22-29)
.5 (30+)
.6 (Total)
Standard deviation: .8 (Total)

TABLE B.8

CLIENT DECISION MAKING INDEX

PERSON RESPONSIBLE FOR MAKING CLIENT - RELATED DECISIONS	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Getting to work on time:				
1-Client	27	22	25	25
0-Other	72	76	71	73
0-Don't know	2	2	4	3
Choosing clothes:				
1-Client	66	66	62	64
0-Other	34	33	37	35
0-Don't know	0	1	0	0
Inviting friends over:				
1-Client	45	47	38	44
0-Other	48	48	57	51
0-Don't know	7	5	4	6
Going to bed:				
1-Client	58	76	76	70
0-Other	41	24	23	30
0-Don't know	0	0	0	0
Spending money:				
1-Client	30	24	26	27
0-Other	70	74	74	72
0-Don't know	0	2	0	0
Buying clothes:				
1-Client	29	22	28	26
0-Other	70	77	72	73
0-Don't know	0	1	0	0
Recreation:				
1-Client	40	44	48	44
0-Other	58	53	49	53
0-Don't know	2	3	3	2
Work or training/activities:				
1-Client	25	30	36	30
0-Other	73	69	60	67
0-Don't know	2	2	4	2

No. of cases: 577
No. of items: 8
Range of values: 0 = minimum
8 = maximum

$\bar{X}$ Scores: 3.2 (16-21)
3.3 (22-29)
3.4 (30+)
3.3 (Total)
Standard deviation: 2.3 (Total)

TABLE B.9

COMMUNITY ACTIVITY INDEX

DURING PAST MONTH THE CLIENT	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Went to restaurant:				
1-At least once	90	86	80	85
0-Not at all	9	13	20	14
0-Don't know	1	1	0	1
Went shopping:				
1-At least once	85	83	81	83
0-Not at all	14	16	16	15
0-Don't know	1	1	3	2
Went to movies/sports:				
1-At least once	55	47	27	43
0-Not at all	44	52	72	56
0-Don't know	1	1	1	1
Visited friends:				
1-At least once	82	70	75	75
0-Not at all	17	30	25	24
0-Don't know	1	0	1	1
Played sports:				
1-At least once	60	36	40	40
0-Not at all	38	62	58	58
0-Don't know	1	2	2	2
Walked or rode bike:				
1-At least once	64	60	61	62
0-Not at all	35	29	38	37
0-Don't know	1	1	1	1

No. of cases: 577
No. of items: 6
Range of values: 0 = minimum
6 = maximum

$\bar{X}$ Scores: 4.4 (16-21)
3.8 (22-29)
3.5 (30+)
3.9 (Total)
Standard deviation: 1.4 (Total)

TABLE B.10

COMMUNITY MOBILITY INDEX

MODE(S) OF TRANSPORTATION CLIENT USES	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Walking or wheelchair:				
1-Yes	73	66	67	69
0-No	27	33	33	31
0-Don't know	0	0	0	0
Riding bike or moped:				
1-Yes	40	26	20	28
0-No	60	73	80	71
0-Don't know	1	0	0	1
Taking bus:				
1-Yes	64	56	58	59
0-No	35	44	42	40
0-Don't know	1	0	0	0
Taking taxi:				
1-Yes	7	12	17	12
0-No	91	88	82	87
0-Don't know	2	1	2	2
Driving himself:				
1-Yes	3	2	2	2
0-No	96	97	97	97
0-Don't know	0	0	0	0

No. of cases: 577
No. of items: 5
Range of values: 0 = minimum
5 = maximum

$\bar{X}$ Scores: 1.9 (16-21)
1.6 (22-29)
1.6 (30+)
1.7 (Total)
Standard deviation: 1.0 (Total)

TABLE B.11

NEIGHBORHOOD ACCESSIBILITY INDEX

RESIDENCE IS IN WALKING DISTANCE OF	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Neighbors:				
1-Yes	98	96	96	97
0-No	1	4	3	2
0-Don't know	0	0	1	0
Bus stop:				
1-Yes	71	71	68	70
0-No	29	28	30	29
0-Don't know	0	0	2	1
Park:				
1-Yes	60	59	54	58
0-No	40	41	44	42
0-Don't know	0	0	2	1
Grocery store:				
1-Yes	80	75	78	78
0-No	20	25	21	22
0-Don't know	0	0	1	0
Other stores:				
1-Yes	58	47	50	52
0-No	42	52	49	48
0-Don't know	0	0	1	1

No. of cases: 577
No. of items: 5
Range of values: 0 = minimum
5 = maximum

$\bar{X}$ Scores: 3.7 (16-21)
3.5 (22-29)
3.5 (+30)
3.5 (Total)
Standard deviation: 1.4 (Total)

TABLE B.12

PARENT PERCEIVED RESTRICTIVENESS INDEX

HOW MUCH PARENTS FEEL THAT HAVING A HANDICAPPED CHILD	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Restricts family activities:				
1-None	43	51	52	48
2-Some	34	29	24	29
3-A lot	22	18	21	20
0-Don't know	1	2	2	2
Restricts opportunity to pursue interests:				
1-None	32	47	44	41
2-Some	44	32	30	35
3-A lot	24	21	24	23
0-Don't know	0	0	3	1
Restricts opportunity to work outside home:				
1-None	42	54	46	47
2-Some	22	19	20	20
3-A lot	34	24	30	29
0-Don't know	3	2	5	3

No. of cases:	577	$\bar{X}$ Scores:	5.6 (16-21)
No. of items:	3		5.0 (22-29)
Range of values:	3 = minimum		5.1 (30+)
	9 = maximum		5.2 (Total)
		Standard deviation:	2.1 (Total)

TABLE B.13

FAMILY SUPPORT SERVICES INDEX
(PROVIDED BY DDD)

DURING PAST YEAR CLIENT RECEIVED	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Respite care:				
1-Yes	34	13	13	20
0-No	64	87	86	79
0-Don't know	1	0	1	1
Special equipment:				
1-Yes	1	2	2	2
0-No	98	98	97	98
0-Don't know	0	0	0	0
Money to remodel home:				
1-Yes	0	1	0	0
0-No	99	99	100	99
0-Don't know	1	0	0	0
Therapy:				
1-Yes	6	5	1	4
0-No	94	95	98	96
0-Don't know	0	0	0	0
Attendant care:				
1-Yes	4	2	5	4
0-No	94	98	94	96
0-Don't know	1	0	1	1
Counseling:				
1-Yes	5	3	2	3
0-No	94	97	97	96
0-Don't know	1	0	1	1

No. of cases:	577	$\bar{X}$ Scores:	.5 (16-21)
No. of items:	6		.3 (22-29)
Range of values:	0 = minimum		.2 (30+)
	6 = maximum		.3 (Total)
		Standard deviation:	.6 (Total)

TABLE B.14

TOTAL HOURS PER WEEK
SPENT IN SCHEDULED ACTIVITIES
(WORK, SCHOOL AND TRAINING PROGRAMS)

Number of hours:	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
0	17	37	44	32
1-9	2	7	2	4
10-24	9	20	18	15
25-34	65	22	24	36
35 and above	7	14	12	12

Note. The percentages of clients with no hours in scheduled activities are slightly higher than the data reported in Figure 3.2, due to 12 cases in which these data were incomplete.

* $p < .05$

TABLE B.15

ADEQUACY OF FAMILY SUPPORT SERVICES RECEIVED THROUGH DDD

DDD SERVICES CONSIDERED ADEQUATE	16-21 (N=195) %	22-29 (N=192) %	30+ (N=190) %	TOTAL (N=577) %
Respite care:				
Yes	30	12	12	18
No	4	2	1	2
Not applicable a/	66	87	87	80
Special equipment:				
Yes	1	2	2	1
No	0	0	0	0
Not applicable a/	99	98	97	98
Money for remodeling:				
Yes	0	1	0	0
No	0	0	0	0
Not applicable a/	100	99	100	100
Therapy:				
Yes	4	2	1	2
No	1	3	0	1
Not applicable a/	94	95	98	96
Attendant care:				
Yes	4	2	4	3
No	0	0	1	1
Not applicable a/	95	98	94	96
Counseling:				
Yes	4	2	2	3
No	1	0	0	0
Not applicable a/	95	97	97	96

a/ Only asked of those respondents who reported currently receiving a particular family support service.